



Routes to Diagnosis 2006-2013, preliminary results

National Cancer Intelligence Network Short Report

Background

Since the publication of the Cancer Reform Strategy¹ in 2007 and continuing with Improving outcomes: a strategy for cancer², cancer survival has been a key area for improvement in England. Compared to the European average cancer survival in England is low³. Studies suggested this difference could be largely due to later diagnosis, when cancers have progressed to a more advanced stage and are harder to treat.

The National Awareness and Early Diagnosis Initiative (NAEDI) aims to increase the number of people diagnosed early. Increasing early diagnosis should improve survival in England, so that it approaches levels seen in comparable European countries. Many research programmes and campaigns for increased cancer awareness have been conducted under the NAEDI banner and a number of government policies instigated. Most recently, the Independent Cancer Taskforce⁴ outlined further priorities around early diagnosis.

One key piece of this work, published by Elliss-Brookes et al. in 2012, defined a methodology to determine the route a patient took through the healthcare system before receiving a cancer diagnosis. Routes to diagnosis³ found large differences in how patients were diagnosed and large variation in survival between these groups. In particular it was found that one in four cancer patients were diagnosed as an emergency presentation, and that this route was associated with low survival.

As of 2015 much activity has been focused on changing the distribution of these routes to help improve survival and this may help measure the success of early diagnosis initiatives. Routes to diagnosis data are being updated and some preliminary results are now available for further study.

Key messages

- preliminary routes to diagnosis data are available for 2006-2013 for the first time
- the proportion of cancers diagnosed through emergency presentations continues to decrease, now at one in five cancers in 2013
- the proportion of cancers diagnosed through the two week wait has increased

1 www.ncin.org.uk/databriefings

Introduction

Presented here are the preliminary results from the fourth iteration of the Routes to diagnosis project. Updated data are presented covering 2006 to 2013, with 2011-2013 being published for the first time. These data show the proportion of patients diagnosed by route and by year in England.

Breakdowns by cancer site, year, sex, age, deprivation and ethnicity will be made available on the National Cancer Intelligence Network (NCIN) website⁵. Cancer screening data for cervical and bowel cancers are unavailable at the time of publication, and once these datasets are added the full cohort of results will be made available.

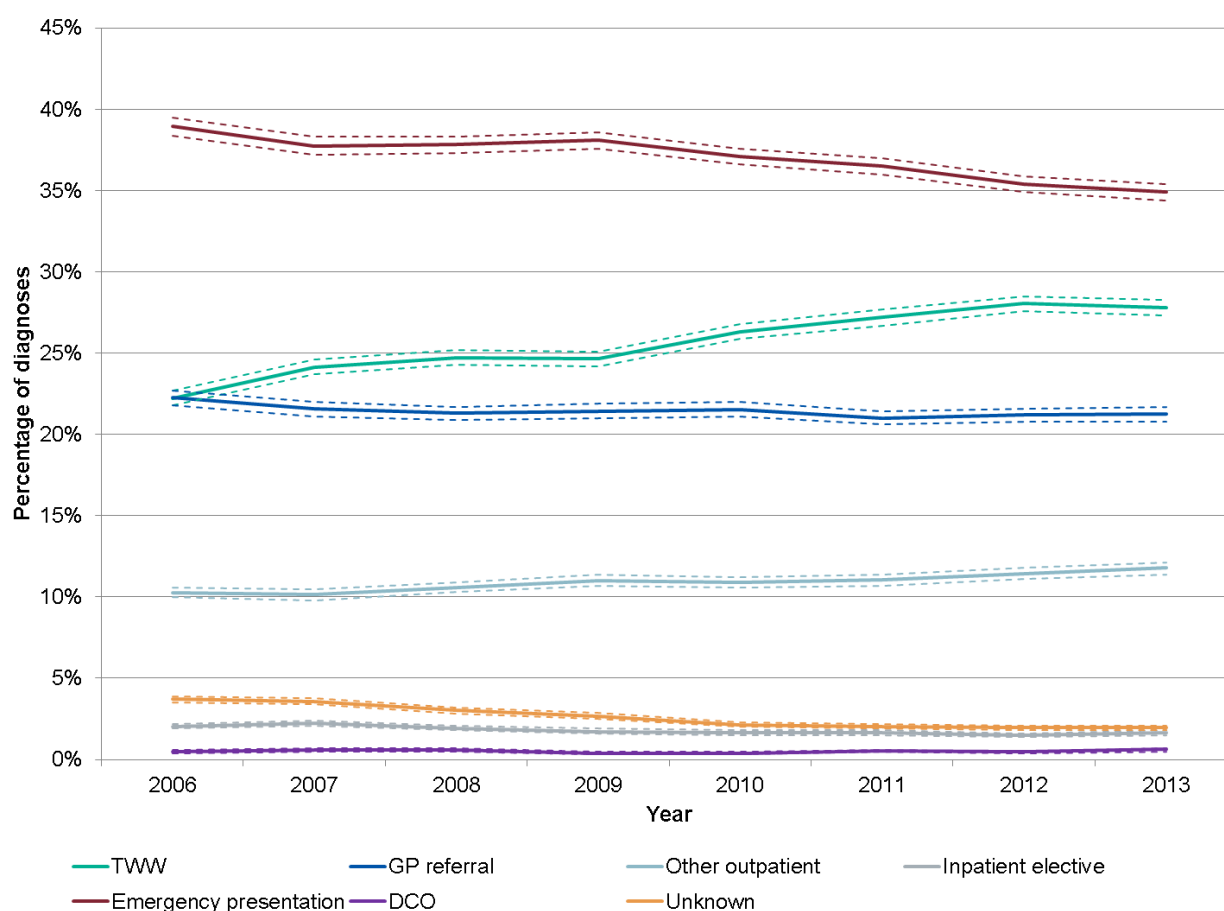
A route describes the end point of a pathway a patient follows to a diagnosis of cancer. There are eight aggregated routes derived from multiple linked data sets:

- screen detected: detected via the breast, cervical or bowel screening programmes; screening data for cervical and bowel cancer are not available at the time of publication
- two week wait: urgent GP referral with a suspicion of cancer, using the two week wait (TWW) guidelines
- GP referral: routine and urgent referrals where the patient was not referred under the two week wait referral route
- other outpatient: an elective route starting with an outpatient appointment: either self-referral, consultant to consultant or other referral
- inpatient elective: where no earlier admission can be found prior to admission from a waiting list, booked or planned
- emergency presentation: an emergency route via A&E, emergency GP referral, emergency transfer, emergency consultant outpatient referral or emergency admission or attendance
- death certificate only: no data available from Inpatient or outpatient Hospital Episode Statistics (HES), cancer waiting times (CWT), screening and with a death certificate only diagnosis flagged by the registry in the cancer analysis system
- unknown: no data available from inpatient or outpatient HES, CWT, screening within set time parameters or unknown referral

Preliminary results

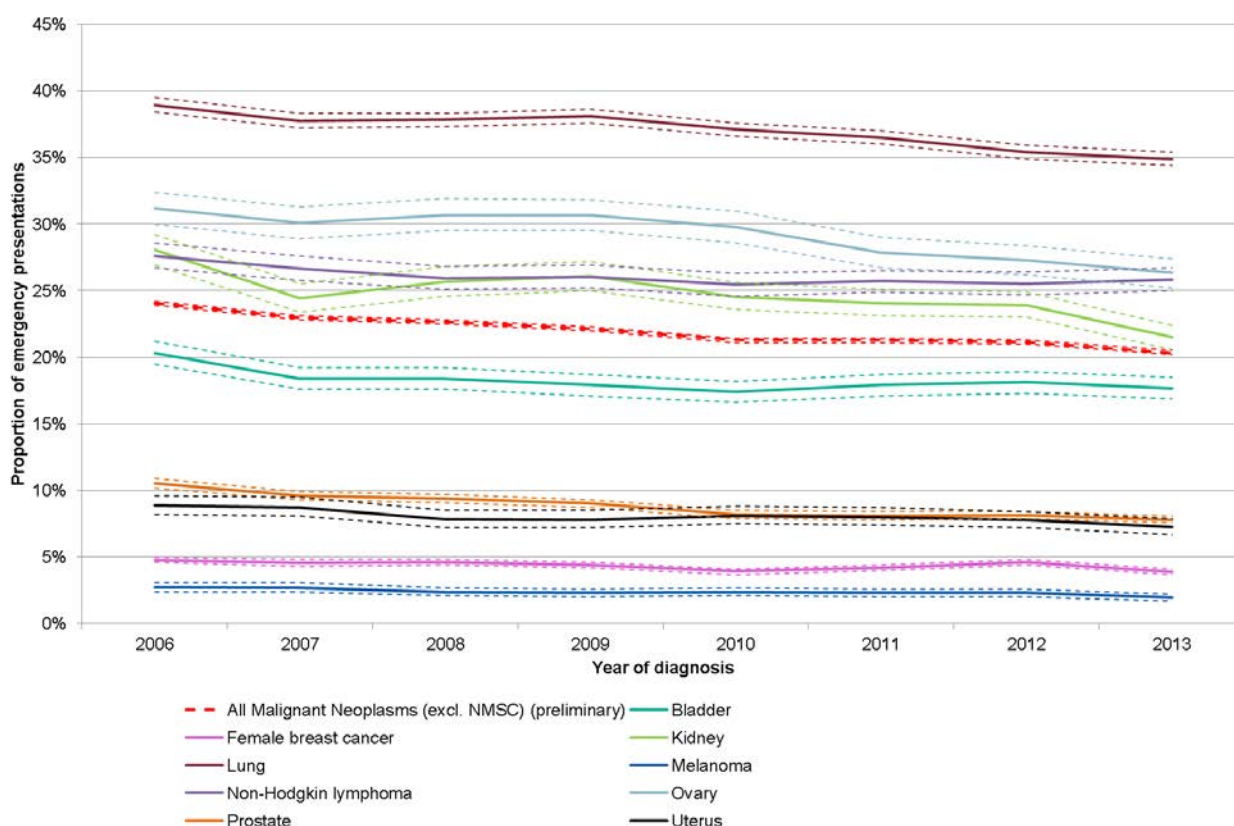
All cancers in England diagnosed between 2006 and 2013 were assigned a route. Lung cancer is used below to illustrate trends seen for each route. The full selection of results, including breakdowns by cancer site, year, age, deprivation and ethnicity will be available from the NCIN website⁵.

Figure 1.0 Routes to diagnosis for lung cancer by year, persons, England



- screening data is not applicable to lung cancers, with no national screening programme active during the time period here
- TWWs increase throughout the period here from 22% in 2006, levelling off in 2008 then rising again after 2009 to 28% in 2013. Several Be Clear on Cancer campaigns targeted lung cancer, running nationally in 2012, 2013 and 2014
- emergency presentations make up the largest single route for lung cancer, however, this proportion falls each year from 39% in 2006 down to 35% in 2013, in line with the TWW increase. In later years the Be Clear on Cancer campaigns may be having an impact in reducing this route. The decline in emergency presentations seen for lung is evident in many other cancer sites

Figure 2.0 Emergency presentations for 10 cancer sites by year, persons, England



- the proportion of all malignant neoplasms diagnosed as an emergency has decreased since 2006; note that this figure is preliminary and does not account for cervical or bowel screening data and so should be interpreted with some caution
- falls in emergency presentations are seen in many sites, lung falling from 39% to 34% and ovary from 31% to 26% as well as smaller decreases with melanomas and female breast cancer falling by 1%; it is worth noting that generally where emergency presentations are already low that the decreases are smaller, with larger falls where proportions start off higher
- Abel et al.⁶ note that this is a statistically significant decrease over time for 2006-2010, and new data shows this to continue for more recent years
- national Be Clear on Cancer campaigns have been run for lung, breast cancer in the over 70s, bladder and kidney cancers and for colorectal for 2012 and 2013, and these may have contributed to the fall in emergencies seen here
- emergency presentations have low relative survival outcomes compared to other routes, so a reduction in the proportion of patients diagnosed as an emergency should increase relative survival
- in 2006 almost 25% of cancers, one in four, were diagnosed as an emergency; while in 2013 this figure was closer to 20%, or one in five – this is against a rise overall in the numbers of cancers for many sites

Methodology

The Routes to diagnosis methodology is described in detail in the British Journal of Cancer article 'Routes to Diagnosis for cancer - Determining the patient journey using multiple routine datasets'³, a brief summary is provided below to aid interpretation of the results presented.

All newly diagnosed malignant cancers excluding non-melanoma skin cancer, and including selected benign and in situ tumours, diagnosed between 2006 and 2013 in residents of England were extracted from the cancer analysis system (CAS). These records were linked at patient level to admitted patient care (Inpatient) and outpatient Hospital Episode Statistics (HES) datasets; the national Cancer Waiting Times (CWT) monitoring dataset and national breast screening data. National bowel and cervical cancer screening data will be linked once available. It is known that the identification of screening as a route for cervical cancers is not fully representative.

Firstly, HES data were used to categorise the route for each cancer individually. Screening and CWT data were then examined with the route assignment potentially changing to either a screening or two week wait (TWW) route.

For patients with HES activity, a specific inpatient or outpatient episode was identified in HES as the end-point of the route by its proximity to the date of diagnosis. The end-point was assumed to be the clinical care event that led most immediately to diagnosis. From this episode HES data were examined to work backwards through the hospital journey to identify a start-point of the route: the initial referral into secondary care. The characteristics of this start-point enabled an initial route to be assigned.

For cases with no HES activity in the six months prior to date of diagnosis, the route was classified as unknown or death certificate only (DCO).

After routes were allocated to each case from the HES data, screening and CWT data were examined. Where a case could be linked to an urgent referral for suspected cancer it was classified as a TWW route, unless the route (categorised using HES data) was an emergency presentation with an admission date within 28 days prior to the decision to treat date. Where the case could be linked to a screening event it was classified as a screening route. If both screening data and TWW data were available for a patient then a screen detected route took priority over a TWW.

Further information

A great many resources and publications are available on Routes to diagnosis. These will be updated as new data becomes available.

Workbooks – the [NCIN website](#) has a number of MS Excel workbooks that have breakdowns by route, cancer site, sex, age, deprivation quintiles and ethnicity. A further workbook will be added in the future with more detail on the emergency route and breakdowns by clinical commissioning group (CCG) and Strategic Clinical Network (SCN) geographies.

Technical document – the [NCIN website](#) hosts a document describing in detail the methodology and data sources used to produce Routes to diagnosis.

Reports and briefings – several reports and briefings are available in addition to this one. Previous publications include a report on [cancer of unknown primary](#) by route, a [comparison](#) of several studies to routes and a more detailed examination of the [emergency](#) route. A [poster](#) with day of week data is also available.

Peer Review papers – a large number of journal articles focus on, use or cite data from Routes to diagnosis. A selection of these papers can be found below:

- Routes to diagnosis for cancer – determining the patient journey using multiple routine data sets – available [here](#)
- emergency presentation of cancer and short-term mortality – available [here](#)
- cancer-specific variation in emergency presentation by sex, age and deprivation across 27 common and rarer cancers – available [here](#)

References

1. Department of Health (2007) Cancer Reform Strategy. Department of Health: London, England. [Report](#)
2. Department of Health (2011) Improving Outcomes: A Strategy for Cancer. Department of Health: London, England. [Report](#)
3. Elliss-Brookes L, McPhail S, Ives A, Greenslade M, Shelton J, Hiom S, Richards M (2012) Routes to diagnosis for cancer—determining the patient journey using multiple routine data sets. Br J Cancer 107(8): 1220–1226. [Article](#)
4. Independent Cancer Taskforce [Report](#).
5. National Cancer Intelligence Network (NCIN) [website](#).
6. Abel G, Shelton J, Johnson S, Elliss-Brookes L, Lyratzopoulos G (2015) Cancer-specific variation in emergency presentation by sex, age and deprivation across 27 common and rarer cancers. Br J Cancer 112: 129–136. [Article](#)

FIND OUT MORE:

Routes to diagnosis data are available from the NCIN website:

www.ncin.org.uk/publications/routes_to_diagnosis

Other useful resources within the NCIN partnership:

What cancer statistics are available and where can I find them?

www.ncin.org.uk/publications/reports

Public Health England's National Cancer Intelligence Network (NCIN) is a UK-wide initiative, working to drive improvements in cancer awareness, prevention, diagnosis and clinical outcomes by improving and using the information collected about cancer patients for analysis, publication and research.

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